

# VIEWS & REVIEWS

## The Alzheimer's Society, drug firms, and public trust

PERSONAL VIEW **Iain Chalmers**

**F**or about five years before he died, my father had Alzheimer's disease. When it was first diagnosed we asked him how he wished his condition to be described when other people asked us about his health. He chose "bewildered"; and, indeed, bewilderment characterised his slow decline over the next five years. By far the most important part of his care was the loving support he received from a carer, who helped our family to cope.

We briefly considered the possibility of drug treatment at one point. The particular drug that we looked at caused diarrhoea in some patients, and that was not going to be welcome in someone who was already incontinent of urine and faeces. But the main problem was that we couldn't interpret the outcome measures from research studies (often scales of some sort). Although sufficient to secure drug marketing licences they had little practical meaning in my father's bewildered life.

In a paper published in 2001 Julia Cream and Harry Cayton of the Alzheimer's Society drew attention to this problem—the mismatch between the outcome measures used by researchers assessing the effects of drugs or other interventions for dementia and the manifestations of dementia that were rated most important to people with the condition and those caring for them.

This mismatch was probably one of the important factors in prompting the Alzheimer's Society to launch its "quality research in dementia" programme, in which patients and carers were integrated into the charity's decision making processes. The Alzheimer's Society was the first large medical research charity in the United Kingdom to do this, and because I have a longstanding interest in promoting such patient and carer involvement, I regarded the society's initiative as a beacon to other funders of research.

I suppose that it is particularly because I used to regard the society as a trail blazer that I have been disappointed by its recent



**Challenging NICE: Neil Hunt, Alzheimer's Society chief executive (centre), outside the High Court**

alliance with drug manufacturers in bringing the first legal challenge to judgments reached by the National Institute for Health and Clinical Excellence (NICE). On 10 August Justice Linda Dobbs ruled against the alliance of the Alzheimer's Society and drug manufacturers on five of the six charges they had brought against NICE (*BMJ* 2007;335:319).

NICE is an independent body established to tackle the difficult—some would say near impossible—but essential task of trying to judge how the resources of the NHS can be used effectively and equitably in a service built on the principles of shared risk and social solidarity. This process is bound to result in "winners" and "losers," but those like the Alzheimer's Society that now regard themselves as losers must make it clearer whether they support the principles upon which NICE was established.

I find it disturbing that in response to the legal judgment, Neil Hunt, the society's chief executive, stated, "NICE failed to listen to the views of thousands of carers who told them drug treatments make a huge difference to their lives. It is deeply disturbing that a public body, required to use rigorous standards of evidence based

decision making, can simply guess at vital data. This is simply unacceptable . . . To retain its authority as a public body it must command the confidence of the public. The result of this case must call into question whether NICE has lost that confidence."

But how might the Alzheimer's Society's close alliance with drug manufacturers erode its own authority as a charity subsidised by the public—which thus also needs to retain the public's confidence? The society could take the following steps to restore my respect for and confidence in it.

Firstly, it should declare clearly on its website the sources and amounts of support it receives for its work.

Secondly, having challenged NICE's judgments about the most effective use of NHS resources for the care of people with dementia, the society should make clear what alternative distribution of limited resources it regards as more appropriate—and why.

Thirdly, it should campaign for treatments for dementia to be evaluated using outcomes that are meaningful to patients and carers, and challenge the licensing and use in the NHS of any new drugs that fail to conform to these expectations.

Fourthly, it should insist that all data from clinical trials are published and that anonymised data for individual patients are made available, so that researchers can try to identify which patients are most likely to be helped by treatments and which patients are unlikely to benefit or may be harmed.

These steps would be more effective and enduring ways for the Alzheimer's Society to serve the interests of people with dementia and their carers than forming alliances with organisations with vested commercial interests to take a public body to court.

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**Competing interests:** The author is a member of the NICE research and development advisory committee and provided written evidence challenging the Alzheimer's Society's charge that NICE's assessment and consideration of the AD2000 study (of donepezil in Alzheimer's disease) was irrational.

William Battie,  
a pioneer in the  
management of  
madness,  
p 403



RCP

## REVIEW OF THE WEEK

## Facebook for scientists?

The Nature Publishing Group has been quick to capitalise on the professional networking capacity of the internet, but is online networking of any use, asks **Deborah Cohen**

"So come on, people, pimp my coat! I'm tired of putting on the same old stained, shapeless one every morning," writes cell biologist Jenny Rohn in her call out to potential collaborators on Nature Network. Rohn, a cell biologist at University College London, met former scientist Wynn Abbott, director of the science art agency SciCult, through Nature Network, a free online networking site for scientists. They started chatting at a Nature Network drinking session and realised that they were both deeply perplexed that the basic design of the white coat has remained unchanged for more than a century. They turned to Nature Network users to look for ideas.

Such collaboration is just one example of the potential networking benefits that the internet offers to scientists. While the Facebook website may already have the monopoly on social networking internationally, the Nature Publishing Group has been quick to capitalise on the professional networking capacity of the internet by launching Nature Network. Although there are other professional networking sites, Nature Network aims to give "scientists a persistent public profile, which lets them find their own voice." This, the creators hope, "will raise the visibility of individual scientists and encourage early collaboration and information sharing."

Currently typical users are in their 20s or 30s, as with Facebook, and doing a PhD or postdoctoral research. Matt Brown, London editor of Nature Network, says that most users are life scientists, but he adds, "The network is equally useful for physicists, chemists, and those working in the health sciences. As well as researchers we also welcome librarians, curators, communicators, event organisers—anyone whose vocation puts them in touch with the scientific or medical world."

Nature Network originated in Boston in February this year as a way to find project collaborators in the area—home to Harvard University, Massachusetts Institute of Technology, and dozens of biotechnology companies. The site wasn't just for Bostonians, claimed Nature Publishing Group: "Locality lets us offer a solid events listing service to which anyone can add events." The site has expanded exponentially since then. A London hub, created in March, now boasts 10 000 UK users; there are several hundred thousand members worldwide.

Nature Network works on two levels. There are the local hubs—Boston and London—where users can meet

local scientists, find events listings, seek jobs, and read articles related to science in those places. And there are the global pages, where users can interact with scientists all over the world, browse and join groups and forums, and read about international science in the blogs.

Each user has a public profile. This lists the user's occupation, interests, projects, publications, and contact details. Users can add other members of Nature Network to their own personal network by searching for them by name, email, or interests. One key feature of the site is the groups, which allow individual communities to have their own space. A diverse range of groups already exists, from those for people working in specific clinical research, such as adult stem cells, to those on broader topics in health and medicine.

Online networks may not replace the bonds that researchers form through meeting someone face to face, but they do have their advantages. Travelling to conferences can be time consuming and expensive, and meeting future collaborators relies, in part, on chance. One of the main advantages of such networks is that you can find people with similar research interests easily and start a dialogue from the comfort of your desk—and all for free. There's also the environmental advantage.

However, the ability to post any scientific comment on the network has drawn criticism. Users have to register to post information and have a profile, but anyone can read the postings in the groups and forums and read the profiles. The main concern about all this hinges on the lack of peer review. Brown argues that the facility whereby anyone can flag up things for moderation is a form of peer review. "The network isn't intended as a place to publish experimental results—that's still the remit of the scholarly journal," he says. Brown thinks, though, that contributions on such sites might be citable on CVs. "If a blog post is well done and attracts intelligent comments it's an easily accessible demonstration that the candidate is good at communicating—much better than just writing 'I am a good communicator' on your CV," he says.

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**Nature Network**  
<http://network.nature.com>  
A free online networking  
site for scientists  
Rating: ★★☆☆



BARBARA JENKINS/NIOSH/CDC

**One of the main advantages is that you can find people with similar research interests easily and start a dialogue from the comfort of your desk**

# Dying to get home

FROM THE  
FRONTLINE  
Des Spence



I love London—its size and the crush of all the world's humanity. Most of all I love the anonymity, the freedom. It was a similar experience when I used to walk the hospital wards: vast institutions and thousands of people wandering the corridors with their own lives and stories. I was constantly on the move, and, tired and irritable, I often worked way beyond the limits of my ability and training. Faces and families spun and blurred together.

I became indifferent to death. Each death was a release: no more infusions, investigations, and all the other endless interventions that defined care. Why couldn't we be honest and tell these patients it was hopeless? Why not send them home and spare them the indignity of yet more mechanised medicine? Instead, in the dead of night I recited in monotone to the family my word perfect, psychobabble death speech. Emotional detachment was encouraged; "Don't get too involved" was repeated a thousand times. This was the collusion of anonymity: so many people were involved and responsibility so divided that the patients and families became emotionally invisible to us. I would like to say that things

have changed, but we are fast becoming just another faceless corporation, Medicine Inc.

A good death is a medical priority. Most of us want to die at home with our family around us, but few of us will be this lucky. A home death eases not only the pain of those who are passing but, just as importantly, the pain of those left living. A home death normalises death as the turn of life, something not to be feared but accepted. So why is it so difficult to deliver?

There are many factors, but GPs hold the key. We have the opportunity and experience to tell patients the truth when they are dying. Unfortunately we often abdicate responsibility through the easiest and "best" option, a hospital admission, initiating that chain reaction that denies patients the chance to die at home. GPs could be more questioning of the practice of admitting patients to hospital in the last stages of illness and do much more to coordinate community services. And perhaps it is time to do the unthinkable: to discard our cloak of anonymity and become emotionally involved with our patients.

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# Now wash your hands

PAST CARING  
Wendy Moore



Pontius Pilate washed his hands of blame. Lady Macbeth feverishly tried to scrub away the "damned spot." Yet healthcare professionals have remained resilient to the handwashing message.

Ever since the first tentative hints that a brief encounter with soap and water might be a good idea between examining patients, doctors have guffawed at the suggestion that their healing hands might actually spread disease. Charles White, the obstetrician who helped found Manchester Royal Infirmary, was possibly the first to mention the unmentionable. Observing the high death toll of mothers and babies in obstetrics practice, White advocated cleanliness as far back as 1777. He was rewarded for his insight by hostility and incredulity.

Less than 20 years later, the Scottish physician Alexander Gordon met with a similar response when he blamed midwives and obstetricians for transmitting puerperal fever between patients. His 1795 treatise urged that nurses and doctors "ought carefully to wash

themselves." And he observed sadly, "It is a disagreeable declaration for me to mention, that I myself was the means of carrying the infection to a great number of women."

Disagreeable as it was, Gordon's message was obstinately ignored until Oliver Wendell Holmes, a Boston physician who was also a popular poet, revived the call. There was little rhyme but much reason in his 1843 essay "The Contagiousness of Puerperal Fever." Recounting the evidence that practitioners were transmitting infection to their patients, especially after post-mortems, Holmes urged a rigorous routine of handwashing as well as gaps between attending autopsies and deliveries. But he was roundly mocked by his contemporaries, including Philadelphian obstetrician Charles Meigs who threw up his pus encrusted hands in horror and declared: "I never was the medium of this transmission."

Most famously, the Hungarian physician Ignaz Semmelweis studied mortality rates on the maternity wards of Vienna General Hospital

in 1847. Observing that women giving birth on the midwife-led clinic were four times less likely to die from puerperal fever than their counterparts labouring on the ward run by doctors, Semmelweis realised that doctors were transmitting disease from the corpses they dissected to the women they delivered. Having himself conducted more autopsies than any of his colleagues in his quest for knowledge, poor Semmelweis miserably concluded that "only God knows the number of patients who went prematurely to their graves because of me."

Semmelweis failed to convince his fellow medics and died ignobly in an asylum.

So if England's chief medical officer, Sir Liam Donaldson, despairs that the handwashing message has still not sunk in with an estimated 40% of healthcare professionals today, at least he knows he stands hand in hand with many unheeded predecessors.

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# Resistance to good sense

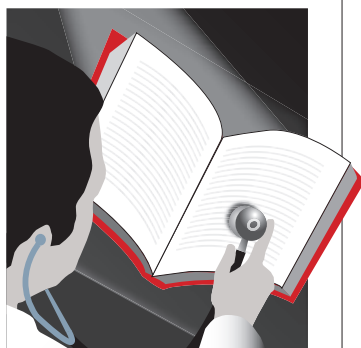
When I was young I thought that people always acted in their own best interests (it didn't occur to me to examine my own behaviour in this respect to see whether it was true). Tell them what was good for them, and they would do it. When they didn't do it I assumed they were deaf and hadn't heard properly; I repeated myself, only a little louder and more emphatically.

Dostoyevsky was under no such misapprehension about his fellow beings. The anonymous narrator of his *Notes from the Underground* starts by telling us that he is sick, although he does not know from what illness. He has the greatest respect for the medical profession, he says (adding that this is because he is very superstitious), but he does not consult a doctor or take treatment—out of spite. He knows that doctors will not suffer if he does not consult them or follow their advice, but still he persists. He would rather get worse than give in.

I think we've all known people like that. But the narrator's problem or sickness is not so much physical as metaphysical. He has seen through the optimistic spirit of the age according to which, if only people saw their true best interests and acted in accordance with them, life would be uniformly happy.

Our underground man, who retired from his civil service position at the age of 40 to live in abject poverty, does not agree. Supposing everyone behaved rationally, according to the best utilitarian tenets, and supposing society had been reformed so that there were no governmental or administrative obstructions to perfect happiness, what then? Will everyone be content to live happily ever after? By no means: "What about all those millions of incidents

BETWEEN  
THE LINES  
Theodore Dalrymple



Some people have a butterfly tattooed on their left buttock or right ankle; others refuse to take their pills. I even sometimes forget them myself

testifying to the fact that men have knowingly, that is in full understanding of their own best interests, put them in the background and taken a perilous and uncertain course not because anybody or anything drove them to it, but simply and solely because they did not choose to follow the appointed road, as it were, but wilfully and obstinately preferred to pursue a perverse and difficult path, almost lost in the darkness? This shows that obstinacy and self-will meant more to them than any advantage."

Does this not accord with our clinical experience better than the simple minded notion that, once the advantages of a treatment are pointed out to a patient, nothing much else remains to be done and the patient will simply follow instructions?

The ways of self destruction are infinite. How many times, when I have been talking to a patient whose self destructiveness seems almost rococo in its inventiveness, have I not thought of this passage from *Notes from the Underground*? "After all, this height of stupidity, this whim, may be for us . . . the greatest benefit on earth, especially in some cases . . . because it does at any rate preserve what is dear and extremely important to us, that is our personality and our individuality."

Especially in the modern world, where to fail to stand out in some way is to fail properly to exist, resistance to good sense is a way of asserting oneself—perhaps the only way. Some people have a butterfly tattooed on their left buttock or right ankle; others refuse to take their pills. I even sometimes forget them myself.

Theodore Dalrymple is a writer and retired doctor

## MEDICAL CLASSICS

**A Treatise on Madness** By William Battie

First published 1758

William Battie (1703-76) was one of the most eminent psychiatrists of 18th century Britain. Educated at Eton and Cambridge, Battie was a fellow of the Royal Society and a fellow and later president of the Royal College of Physicians. He was reputed both for his scholarly work (including an edition of Aristotle's *Rhetoric*) and his anatomical demonstrations. Yet it was the "mad business," as he described it, that really caught his imagination. Already a governor at Bethlem Hospital and owner of two other private institutions, Battie was the founding physician of St Luke's Hospital in 1751. Situated opposite and in competition with Bethlem, he hoped that this new asylum would bring an unprecedented standard of care for the insane. Indeed, it could be argued that at St Luke's attempts were made, for the first time, at the structured "management" of mentally ill people.

*Treatise on Madness* was a seminal work in psychiatry. Although there were important earlier works, such as Timothy Bright's *Treatise of Melancholy* (1586) and Robert Burton's *Anatomy of Melancholy* (1621), Battie's work was the first specifically on "madness." It arrived at a time when psychiatry, still far from an established discipline, continued to experience therapeutic stagnation and professional apathy. It was Battie's intention to remove some of the antiquated ideas about insanity, many of which, he believed, stemmed from the physicians at Bethlem. Instead he admired



the physiological advances of medical theorists such as Hermann Boerhaave and Albrecht von Haller and looked to use them in his practice.

A number of Battie's convictions stand out. He promoted the idea that mentally ill people should not be detained just to protect patients and society.

Moreover, patients could derive direct therapeutic benefit from spending time in a psychiatric institution. In contrast to much scepticism regarding the curability of mental illness, Battie asserted that madness was "as manageable as many other distempers." Finally, Battie proposed a division of madness into "original" and "consequential" illnesses, forerunners to the "organic" and "functional" terms used to this day.

Battie's ideas were not entirely well received. The Bethlem physician John Monro took issue with a number of Battie's central tenets in his reply *Remarks on Dr Battie's Treatise* (1758). Monro endeavoured to counter all of Battie's assertions and ultimately concluded that it was for "the impartiality of the publick to determine between the *Treatise* and the *Remarks*." Indeed the public, as well as the medical profession, did give increasing attention to the subject of madness and madhouses. Furthermore, the internal debate gave rise to several more psychiatric texts. As a result psychiatry was given much needed impetus as a discipline, and Battie's *Treatise* was in many ways the catalyst.

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